

How Pediatric Hematologic and Oncologic Patients Experienced Virtual Learning During COVID-19: Importance of Amplifying the Family Voice for Informing Future Recommendations

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Background: With medical advancements in the detection and treatment of pediatric oncologic and hematologic disorders, survival and life expectancy rates continue to improve. However, the treatments themselves have been linked to long-term cognitive issues (e.g., attention, working memory, and executive functioning). These difficulties have particular salience to academic achievement and often necessitate educational accommodations to support learning. However, these plans are designed for the traditional school environment and may be insufficient for virtual learning. The purpose of this study is to investigate the perceived impact of COVID-19 in the context of virtual learning for children with hematologic or oncologic disorders to inform the development of appropriate recommendations for patients and schools this fall.

Methods: Qualitative interviews assessing academic accommodations and COVID-19 adjustments to virtual learning were conducted separately with participants and their guardians by phone. Medical histories were obtained via electronic health record.

Results: Thirty children (*Mean*=12.8 years, *SD*=1.4 years) with status post cancer treatment (*n*=17), sickle cell disease (*n*=11), or neurofibromatosis type 1 (*n*=2), with an IEP (*n*=15) or 504-plan (*n*=15) in place prior to COVID-19. During virtual learning, children reported a lack of interaction with teachers or other resource help. Guardians felt pressured to assist with schoolwork without sufficient support or qualifications. Anecdotally, families still expressed gratitude to their schools and teachers, revealing overall low expectations for virtual learning.

Potential Impact: This pediatric population faces unique education challenges, specific to neurocognitive impairment secondary to their chronic health conditions. Unsurprisingly, families perceived that their educational needs were not met during virtual learning related to COVID-19. To prevent the cascading effect of insufficiently addressed academic needs, the inclusion of family's perceived experiences is critical for informing individual recommendations and the Indiana Department of Education broadly during the transition back to school this fall, both in the physical and virtual classrooms.